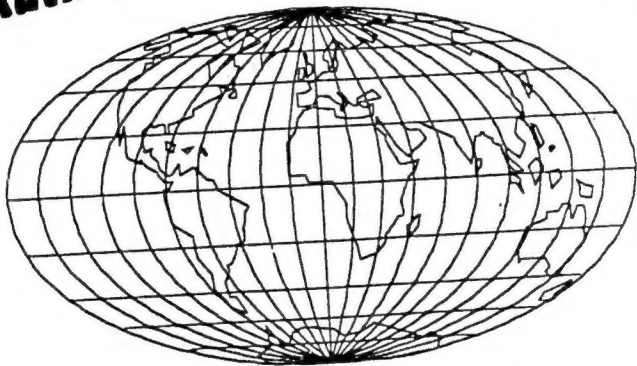


Autism Network International



***Our Voice* Newsletter**

Issue 3

MY PERSONAL HOLIDAY
by Katherine French

On May 15, 1993 I met face to face with Kathy Lissner. I had spoken with other Autistic people on the phone before, but never in the flesh. For me, this day will become an anniversary that I will celebrate with great joy. It marks the beginning of not being an alien. It will be a day of validation. A day to set aside and remember.

Kathy Lissner and her fiancé Ray met me at the St. Louis airport. We shook hands then rode in a taxi to her apartment. I stared out the window and wondered to myself if I was crazy for hopping on a plane, flying to an unfamiliar state to meet unfamiliar people. You see, I still had not yet met Jim Sinclair, who was driving from Kansas to meet with us. During these thoughts a cement wall appeared before my eyes. Racing by at 60 miles per hour. I absolutely hate to drive by cement walls! I closed my eyes and began feeling sick to my stomach. Ray asked what was wrong. He offered to trade places with me, but I had shut down, so I stared at the floor and stayed put. Ray didn't need a lengthy explanation. He didn't tell me I was ridiculous or tell me not to feel how I was feeling. He took a simple, short response and asked if he could help me get out of the situation. I had only stated, "I hate cement walls." I'm quite certain Ray is used to rules that don't pertain to him, but that are idiosyncratic to Kathy.

When we arrived I asked Kathy if we could go for a walk. We had only gone one block when I spotted a friend from long ago. This friend is a shrub. Not just any shrub, but a shrub whose leaves I often snacked on

as a child. Without giving Kathy any warning I squealed with delight as if it were Christmas morning. I picked off some very dark maroon leaves and began eating them. Although she had no background as to my friendship with shrubs such as this one, and although she was only introduced to me an hour before, she did not question my behavior nor look around to see if someone might be watching. It did not occur to her to be unusual or that she ought to be embarrassed by her new friend's actions. Rather this new friend of mine immediately began plucking leaves off the bush and handing them to me. She saw my pleasure and reached out to help! Her reaction was very different from that of a non-autistic friend a year earlier. While walking with a friend in my home state of Indiana I became reacquainted with this shrub after about 12 years of not seeing her. In this case I just stopped and began shoving leaves in my mouth. My friend grabbed my arm and yelled, "What the hell are you doing?" He looked around as there were houses all around and he was concerned that people would think I was nuts. I tried to explain....but the words just weren't there. That night in my journal I wrote that if nothing else of significance happened during this trip that one experience of being understood was worth all the time and expense of coming to St. Louis. I went to sleep feeling I belonged.

A few days later Jim Sinclair joined us for a day at the Gateway Arch. I noticed I was very nervous about meeting him. I had spoken many times on the phone to him and didn't really feel that putting a face and

body to this person felt safe at all. I became very conscious of my outer shell—my body—and robotically walked out to Doyle Cozadd's car to meet a person in the back seat. I became cold and withdrawn and numb. I heard a "hi," I gave him a "hi" back. I turned my head as far left as my neck would crank around to stare out the window into nothingness. At that point I had nothing to interject or ask this person beside me who had touched my world through sound on the telephone. Jim was a sound; I wasn't necessarily interested in his body form. It took away from the voice I had become friends with. Fortunately Jim has a dog named Emmy who kept jumping from the tailgate in between us. She became a safe focal point for me and possibly Jim. I could pet Emmy and talk to her and notice the form beside her. The form had hands that felt the same fur I felt. This slow, unforced, impersonal introduction was what I needed. The common focal point or distraction from ourselves worked great. I felt no need to meet eyes with my new friend or to have insignificant small talk as many people do to get acquainted.

At the Arch my peripheral vision

told me where Doyle, Kathy and Jim were, yet we didn't need to talk to feel secure. It was not an uncomfortable silence. I soon observed I could just "be". I could hardly believe it was true. As we toured the museum we didn't stay in a clique and we didn't have to comment on each display. We all just observed. If one of us did point out something we liked the others didn't need to agree or respond. We didn't expect a response. It was the beginning of my experience of others allowing me to just "be".

My visit to St. Louis literally changed my life. I now know there is a group of people I can spend time with who do not expect me to be any certain way. Not many things surprise them, nor do many things offend them. They do not try to make me like them. They accept my interests and don't try to change them. I believe all persons with Autism need the opportunity to become friends with other Autistic people. Without this contact we feel alien to this world. We feel lonely. Feeling like an alien is a slow death. It's sadness, self-hate, it's continuously striving to be someone we're not. It's waking up each day and functioning in falsehood.

[Katherine French is the designer of this issue's cover.]

ON BEING DIFFERENT
by Jonathan Mitchell

I pretty much began to realize I was different from as long back as I can remember. I can remember shortly before I was five years old my mother explaining to me that I had "problems" that prevented me from going to a public kindergarten. There was this private school kindergarten called Westland School that my mother hoped would take me for kindergarten. My mother explained my situation to the school as best she could. At this point, I don't think she thought of me as being autistic but explained to them that I had problems of some sort. They agreed to try me during a summer session. I still remember my mother telling me that I was not ready to go to kindergarten there. I was not yet five years old but I knew what this meant and this really hurt me. I eventually did go to two different kindergartens, the first one my mother took me out of because she did not get along with the headmistress. The second one, I was expelled from for behavioral problems and just stayed home the remainder of the school year, never finishing kindergarten. It really hurt me that I could not finish kindergarten the way other children could and this really hurt.

Also shortly before my third birthday, I started psychoanalysis, the treatment of choice for persons with autistic-like symptomatology in those days (the late 1950s). My psychoanalyst made it fairly plain that I was a child with problems and that everyone had problems but that mine were worse and more pronounced than others, so this was another realization of my differences. I remember her telling me this at age six.

Also at age six, after having been expelled from the second kindergarten, enrollment in a public

school or any sort of regular school program was out of the question in my parents' mind. I ended up attending a special ed school and was told that "I was not ready" to attend public school and I would have to wait when "I was ready." One of the particular teachers I had would often castigate us for behavior problems and tell us this was why we could not go to public school. He would also show us some videotaped recordings (such as they were in those days of the early 1960s) of children in a regular private school, emphasizing to us how well-behaved they were and how poorly behaved we were. I was led to believe (I might add I now feel this childhood belief was erroneous) that I was unfit to go to public school.

I was also chronically teased and picked on by whatever "peers" that I had so this again was another emphasis upon how I was different. Yes, it was very traumatic.

Unfortunately, this was and has been a dynamic process rather than a static process. In the ensuing years of my life, even though I realized that I was different, more realizations of differences cropped up as I began to grow older. As a child, I always believed that someday I would be able to attend a regular public school, be able to marry as an adult as well as hold down a real, regular job in the real world.

I finally was able to attend public school in a regular classroom setting but I had to wait until I was 14 years old.

Upon reaching adolescence, other boys I knew would boast about how they had kissed girls and had had more than platonic relationships with the opposite sex. By this time I had heard the old saw that those who talk about it the most did it the least as

well as the fact that none of these things that they were talking about had happened to me. For these reasons, I thought they were making these exploits up and I did not believe them. I then discussed it with my psychiatrist, who was my therapist at the time, asking him if boys my age really did the things that these guys I knew claimed they had done. My psychiatrist assured me that they did very emphatically. This was another instance of realizing that I was different. It was not too traumatic at the time as I realized that perhaps I was a late bloomer and that someday my problems would be solved or at least mitigated and my time would come. Of course, I am now 37 years old and have never had a girlfriend and that does hurt and I really don't see any prognosis of the situation getting any better.

Peers still did not want to associate with me, often kicking me out of their homes and giving me a hard time. If I was having a conflict with another child or adolescent, I would often get blamed by the adult who I felt should either be neutral or blame the other person. I could not really understand why I was getting blamed so much but knew it had something to do with my problems. Was I really a bad person that constantly started fights and arguments? I did not know at the time. At other times, I used coping mechanisms of denial, blaming these other people for my problems and not really believing that anything was wrong with me and that somehow these were all very bad people.

Many years later, I came to the realization that the reason for my always being blamed wasn't the fact that I was a bad person or that they were totally prejudiced against me or that these peers that I had conflicts with or the adults that sided against me were bad people. I realized that the reason was my voice was louder

than other people's voices and my behavior was more bizarre which would lead a neutral observer who knew nothing more about the conflict to conclude that I was to blame. This was just human nature. Coming to this realization was a relief to me as I felt that it sort of exonerated me and I knew that it was not because I was a bad person who started fights and/or conflicts. I also realized that all of these people were not bad people but that my problems would just bring out the worst in them.

The realization of being different did not end with the childhood/adolescent period of my life. After I got out of school, I always had trouble holding down a job. I was fired from about 15 jobs in a period of about 11 or 12 years. These accentuated my realization of being different tremendously. Fortunately I was able to get into the field of medical transcription and become more marketable from the point of view of the employer and I thank God that I am currently employed. I know that I have had trouble in the past and there is a good chance that something may go wrong with this job and that my employment problems have not been entirely resolved, but now that I have successfully held down jobs, I am more confident.

As far as advice and the answering of questions to the Reznicks, I think I do have a few things I can say.

I personally do not believe that there are any effective therapies for autism and related conditions. Many of the so-called experts who claim that there are have a financial incentive to make this claim. If your child is seeing a therapist, I would recommend that you discontinue the therapy immediately.

I would also recommend that if and when Abby gets into conflicts with peers, teachers, and others and a

neutral party blames her that the Reznaks explain that the conflict was not necessarily her fault but that her behavior and possibly loud voice will stand out and prejudice people toward her. I wish this had been done for me at an early age, as I did not come to this realization until adulthood.

I would also recommend that the Reznaks obtain some sort of vocational training for Abby at the earliest age possible as this will offset the problems she might have in the job market as an adult due to her disability. Teach her about computers, typing, accounting related things, etc.; whatever she may be best at, at the earliest age possible.

Finally, I would like to say that I agree with the Reznaks that Abby will most likely discover she is different from other children at

some point if she has not discovered so already. In fact, she will have her differences emphasized ad nauseum. For this reason, I would advise the Reznaks to compensate for this by explaining to Abby not how she is different from other children but the ways that she is LIKE other children. Even though she is different than non-autistic children in some respects she is just like them and will be like them in many others. She will want to be popular and accepted by peers. She will want to play with toys and have meaningful hobbies and activities the way other children do. Upon reaching adolescence, she will want to date boys and be recognized by them the way other girls without autism do. She is a feeling human being just as non-autistic children are and in many respects not different than they are. I hope this helps the Reznaks.

WHAT IT'S LIKE BEING AUTISTIC by B.J.

Well, autism for me is like being part of a different culture. You don't know the person but you could learn to like them for who they really are and not for what they have. For example I like Jim for who he is and

not for what he has. Being at the conference really helped a lot. I got to look at autism from different points of view and I also got to meet a lot of, uh, *interesting* people. And I also got William Christopher's autograph.

SUSTAINED EYE CONTACT: ONE WOMAN'S VICTORY
by Geneva Wolf

I grew up wanting to be invisible. After all, if people didn't see me, they wouldn't always be correcting me. I didn't want other people to see the real me, so I avoided allowing them to look inside of me. In other words, I avoided sustained eye contact. Of course I didn't analyze until years later.

As a child I could not handle sustained eye contact. I glanced at people. Any prolonged contact was painful, acutely painful. So I avoided it. I would "check out" with my eyes aimed at them (but out of focus) or staring off in the distance, only glancing at the other person often enough to keep them from walking away.

As an adult, I realized that if I wanted friends, I was going to have to do something about the excruciating pain brought on by sustained eye contact. I decided that "conditioning" was the only viable solution.

To begin the process, I forced myself to look into my own eyes using a mirror. I tried for days before I

experienced any level of success. It took weeks of daily sessions before I could look into my own eyes for more than five seconds. After a couple of months I decided that the pain/panic had subsided far enough for me to try it on another person. I went into a store and asked a question. When the man started to answer me, I forced myself to look into his eyes. I think I lasted about four seconds. So—I said to myself, "If I can last four seconds, then I can last five." So, bit by bit, second by second, I began to recondition myself.

From then on, I ignored the pain in my stomach and head. I refused to react to the sense of panic, and I forced myself to look AT people instead of beyond or beside them, or anywhere else I could escape to.

Today (over a decade later) I can't say that sustained eye contact is always comfortable, but I have grown beyond the pain and panic. Now I can usually carry on a conversation with enough eye contact for the other person to know that I am listening.

Now that's what I call victory!

NEURAL CONNECTIONS IN TORONTO by Steve Cousins

I guess I really should introduce myself first or a lot of this won't make much sense. Not that an introduction will guarantee coherence, but it's worth a try.

Hmm. Where to start. First of all, I'm certifiably brain-damaged, courtesy of a doctor whose arrogance far exceeded his skill and his judgment. The brain damage at birth resulted in hydrocephalus, a condition in which the ventricles of the brain expand with fluid, causing damage to the cerebellum and parts of the limbic system. As a result of this condition, I experience tremor, global motor planning difficulties, poor balance, trouble adjusting to novel situations, and inability to function within a group. I also have functioned as someone who has used fixations on topics during my lifetime as a springboard to learning. I have never officially received a label of any kind, but some of the similarities to high functioning autism/Aspergers should be obvious. I am currently a doctoral student in special education.

The road to Toronto was a serendipitous one. It was also mostly electronic in nature. It all started in the world of computer networking. Last January I joined a discussion list on the Internet devoted to autism and other developmental disabilities. The list consisted (and still does) mostly of parents, a few professionals, and a very few autistic people.

Over a course of months, Jim and I started on regular correspondence. We had found ourselves on the same side of some heated arguments on the discussion list. Eventually we learned how to type to each other in real time over the computer, and our interactions became almost daily.

As a poor, starving grad student, I had made no plans for

attending conferences this year.

This is what I told Jim when he asked me if I was planning on going to Toronto. He then asked me if it would make a difference if I could get cheap lodging. That's when he invited me to camp with ANI just outside of Toronto. I scraped and begged, and came up with the traveling and registration money I needed. The thought of being able to stay with members of ANI was exciting, as was the prospect of meeting Jim, who had already become a good friend. I had attended and presented at conferences before as a professional, but made a conscious decision that I wanted to wear just the "Brain-damage hat" this time out.

So I arrived at the campground, on time, and waited for Jim and the rest of the caravan, who were a day late. Not that I didn't hear from the caravan; well, part of it, anyway. It seemed like every few hours I'd get a new phone message from the camp office that the caravan was late. Finally, I received the somewhat alarming news that Doyle and B.J. had been lost, with the name and phone number of a Michigan State Police officer. The number turned out to be nonexistent. I finally decided to call Doyle's wife Rita to find out what the heck was going on. She said they had heard from Jim (not Doyle) and that she thought they'd finally be on their way soon.

I found out later that Jim had managed to stay behind Doyle for hundreds of miles without losing him in the traffic. Once Jim took the lead, it took about three miles for Doyle to lose contact with Jim. Communication difficulties plus a defective "theory of mind" on the part of the state police resulted in them all being mucho late.

As a result, I got to put up my tent all by myself that first day. I'm

sure it would have been entertaining to watch, had there been an audience. Given my motor planning, it took a great deal of time and fumbling around to finally get my tent up. When I finished, it was kind of lopsided and sagging in places, but it stood. Of course, a lack of wind and/or rain helped.

When Doyle got there, we decided that we only needed one tent and a corner campsite. I dreaded taking down the tent but was thankful I'd have help so it wouldn't take so long to set it up again. Surprise. It took three times as long to put the tent up with Doyle's help as it did to do it alone. (I think Doyle was thrilled to be talking to an adult. I, on the other hand, have to stop working when I'm trying to talk.)

The following are some random bits and pieces mostly stitched together from messages I wrote for the Autism discussion list, where Jim and I first met. With Jim's permission, I have adapted and included a couple of his comments to the list as well. You'll probably notice that I won't talk much about presentations in this piece. I *did* see some. We all did. It's just that it was much more interesting and exciting to meet and talk with autistic people than to hear others talk about them. I am hoping readers will feel the same.

The first day was full of meeting people, setting up, and one rather unpleasant surprise. As a preface, you should probably know that the Autism Society of America likes to say they have a "large tent". This means they refuse to take any stands on issues like aversives or integrated educational settings.

The full reality of ASA's non-position on the use of "aversives" hit me full force early on in the conference. (Interesting euphemism--like the medical use of the word "euthanasia" to describe the killing of infants with disabilities.) Aversives

can refer to slaps, lemon juice squirted in the mouth, electric shock, and spraying people's faces with water. I'm sure there are plenty more. Practitioners of these methods are pretty inventive.

Anyway, I was helping to set up the ANI booth on Tuesday, and decided to check out the other exhibitors. As I rounded a corner a sign at a booth caught my eye. The booth belonged to the Behavior Research Institute. For those of you who aren't aware of BRI--it is a facility that has the dubious distinction of being a true bastion of the use and promotion of aversives.

Contrasted against this was the curious case of another person surreptitiously asking other booths to lay out a few copies of a newsletter on inclusion. She and the others at her booth were denied permission to distribute it at their own display for two reasons. One is that they had not submitted it in time for approval, which, though rigid, is fair, I guess. However, they were *also* told that some attendees might find the newsletter offensive!

We made a somewhat ironic discovery there in the exhibitor hall. One of the Auditory Integration booths was situated right next to BRI (their organization must have drawn the short straw, I guess). The booth had a videotape player hooked up to a monitor. The video machine was usually off, but the monitor was *always* left on, leaving a blank screen. The monitor they had emitted one of the worst high-pitched squeals I have ever heard from such a device. This was nothing most neurologically typical people were aware of. However, all but two HFA's avoided the booth due to the noise. One exception was B.J., who seemed unaware of the awful racket. The other was ASA board member Tom McKean, who sat there for a while in apparent comfort. Maybe the auditory training was of some help to him after all.

A little later on in the conference, Jim and I got a chance to discover that two differently-wired brains are not always an improvement over one. Any time we were alone in the car, we got lost—turning ten-minute drives into two-hour adventures. We both have strategies that help when we're on our own, but seemed to lose them when in close proximity. We concluded that it must be some kind of electromagnetic energies that canceled each other out.

(Doyle suggested he might use some of his meditation skills to somehow harness that electromagnetic energy. I accused him of having a Manhattan Project type of mentality for contemplating such an exercise without first considering the consequences. The earth is still in its proper orbit and I think the cosmos owes me a "thank you" for talking Doyle out of it.)

The first time we were in the car was probably the most severe extreme example. Jim and I drove out from the campground to join the meeting of ANI members that was taking place after dinner. These meetings were held every conference night.

Not that my visual memory is something to count on, but I *know* I got to see the same stretches of highway more times than I could easily count (math isn't one of my strong points, either). We kept going round and round, and it was clear after a while that we had no more idea of how to return to the campground than to get to where we were going. There is a legend of a ship called "The Flying Dutchman" which sails through eternity with a ghostly crew, never making it to home port. I was beginning to wonder if we were about to be the stuff of new legends.

After more than an hour of driving around looking for the hotel, Jim finally spotted it from the highway. It was a huge wide building with enormous letters spelling out its

name on top—very hard to miss. Jim exclaimed, "There's the hotel!" I asked, "Where???" Then I saw it too: "There it is!" We were both very excited. Jim suggested that maybe he should find a place to park so we could look at the hotel from the car, since we weren't likely to get any closer to it if he kept driving.

When we finally *did* get to the hotel, we arrived to find about ten people in the room. There were at least ten separate discussions going on. A video camera that was there to record the historic sharings of autistic people was running unattended and aimed at a nondescript painting on the opposite wall. As I made my way to the far end of the room, Jim hung back and called my attention to the bathroom, which I had passed coming in. Doyle, our camera operator, was getting a haircut from Katherine French. Only one person acknowledged our entry, and that was to ask us what time we'd be returning to the campground!

About that time, one person in the room became distressed over some changes in scheduling. The entire group focused on him and did their best to provide him with some support. Imagine how helpful they could have been if they'd been able to be empathic.

Later in the conference, I got a more direct and personal exposure to the legendary autistic "lack of empathy." While helping at the booth, I was asked to make some more buttons because we were running short. I was shown how to do it *twice* and somehow seemed to remember the proper sequence for making them. However, they still were coming out mangled and useless. Jim looked over and saw my progress (or the lack of it). He said it was obvious that it would take me a large number of repetitions to get the proper "feel" for the process. Since we were short on time and buttons, he suggested it would be better to turn

the task over to someone who'd already gone through the learning process.

This is hardly the first time my motor planning has made the performance of a task noticeably deficient. What was different in this case was the way it was handled. There was no belittling or blaming involved. No criticism of my concentration or motivation. Just an acknowledgment that I needed extra time and tries to learn this thing and that, given the needs at the time (more buttons fast), it would be better to have someone else take over. It was a refreshing experience to have my impairments acknowledged but not be made to feel like a failure in the process.

One of the visitors to the booth was Connie Deming, a woman who has an autistic son. She is also a singer and songwriter. She had a tape of her music that she gave to Jim. One of the songs, "Butterflies," is a beautiful picture of autism.

Jim, Katherine and I tried to listen to her tape at the booth, but there was too much going on for us to be able to concentrate. So we ended up draping the curtain in back of the booth over a couple of chairs. The three of us got behind the curtain to listen to the tape. Unfortunately, this left the table completely unstaffed. I believe we were all visible behind the curtain, though. It *did* make the tape easier to listen to. I wonder how it looked; we never *did* get a picture.

At one point, Jim crawled out to talk to someone who had stopped at the table and was looking over the materials. Jim explained that we were "just back there being autistic." Then again, as Jim commented upon returning to the curtain, the visitor was from Belgium. Jim figured he might have thought huddling behind curtains is just some quaint North American custom.

Almost total lack of sleep (due to *someone's* hearing hypersensitivity and

unwillingness to let a poor exhausted snorer alone) forced me to seek refuge and a nap behind the curtain at the booth so I could stay awake for Eric Courchesne's presentation. I woke up to a wonderful surprise—Jim had made me a special one-of-a-kind ANI button that read "COUSIN" in bright glitter letters.

The button probably merits some explanation. Earlier in the conference I met Kathy Lissner for the first time. Kathy is an absolutely delightful autistic woman. She asked me what I was doing at the conference and essentially what my connection was to autism and ANI. So I gave her a five-minute rundown of my history (neurological, cognitive, behavioral).

Kathy was silent for maybe four seconds. Then she exclaimed, "COUSIN!" and threw her arms around me.

I was impressed. Jim was impressed. I had spent *months* comparing and analyzing differences and similarities with Jim and others. In four seconds she came closer to defining a relationship between my hydrocephalus and autism than any amount of *extensive* discussion with anyone else had resulted in!

This gets to the experience of contrasts in the extreme that emerged throughout the conference. Kathy's autism is viewed by many as meaning she is incapable of the wonderful flash of insight she treated me with. It was the *non*-autistic persons who all too often proved to lack any insight or sensitivity. The following are cases in point:

At the first evening's meeting of ANI members, we had a couple of professional people who were there at the meeting. At the end of the session, Katherine told them that these meetings were really meant for HFAs, since they seldom got a chance to meet with each other. The two professionals in the room appeared to be irritated. They said that this was a wonderful

chance for them to learn. Katherine pointed out that the goal of the meetings was for people to connect and share. The professionals left, expressing a feeling of being excluded. They missed the point. Those meetings were for peers to connect and share with each other, not displays for gawkers, no matter how well-meaning. Besides, I'm sure they, like all professionals, had attended plenty of meetings limited to members only, with no one suggesting they become less exclusive.

It was about that time that I realized with something of a shock that when Katherine had said the meetings weren't for professionals, the message wasn't directed at me. I had never presented myself as a professional and wasn't regarded as such. I had never hidden the fact either. I was there as a person whose experience and neurology gives me a lot in common with other members, and I was accepted as such. It was a nice feeling.

Another example of non-autistic lack of insight, empathy, and sensitivity came at the end of the conference. As we were taking down the ANI booth, some woman came by with a video camera. She turned the camera on Jim and asked him a few questions. I don't know what they were, as I wasn't paying much attention. (All right, I wasn't paying any attention.) This was obviously a mistake.

The next thing I knew the camera was on me and I was being asked how old I am. Fine. No problem. I gave her the answer. Then I got asked what I'm doing. Also fine. I told her I'm a doctoral student. (Actually, I'm not too sure of the order of the first two questions.)

Now, I was fully expecting to be asked what my field of study was. Maybe a question about my research interests. The fact that I was being interviewed as a HFA hadn't fully hit

me. It hit me with the next question. She asked me if I have a *girlfriend*! Too stunned to react to the intrusiveness and inappropriate nature of this question, I answered "no." So next she asked me, "Why not?" It was at this moment that the fragile sense of reality I hold so dear started to disintegrate.

I remember throwing out some syllables to the effect that I had "worked very hard not to have one." I know I was asked more questions, but have only a vague idea of what they were. The same is true for whatever answers I gave.

I still can't believe how bizarre, inappropriate, and presumptuous these questions were. It didn't matter that I was a doctoral student or that I may have had some kind of interesting life. No; because someone had read or heard that autistic people don't form close relationships, the only important thing was whether or not I had a girlfriend. It is ironic that one can spend five days with autistic people and have the most bizarre interaction of the week come about with some non-autistic tourist with a video camera.

Jim told me that I can look forward to more interviews like that if I continue to "come out" as a person with neurological impairment. If that is true, the next time I get asked about not having a girlfriend, I will patiently explain that brain-damaged people don't have enough neural connections to bond in pairs. It takes four of us to form a deep bond and the logistics are so difficult that most of us end up living and dying alone. It will probably end up being quoted in a journal somewhere.

Actually, there was an attempt to form some kind of "group meld." Katherine, Jean-Paul and Doyle scheduled a telepathic conference for 2:15 a.m. one of the conference nights. Jim and I were the only ones who showed up for the conference. At least the others hung out large "do

not disturb" signs where we could perceive them. So I guess the groundbreaking step toward autistic/cousin family groupings will have to wait for another time.

Fortunately, the other people I met more than made up for the typically-brained clod with the video camera. Toby the *almost* always patient. B.J. the *always* friendly. The chance to sit outside and chat with Jean-Paul for a long while, comparing notes on school, frustration and other aspects of life.

While wonderful connections were being made on one front, strange social phenomena emerged on another. An interesting thing I noticed at the conference was the strange but consistent reaction from people I ran into who knew me as a professional and a doctoral student. I was generally asked if I was presenting. I would explain that no, I was here with friends from ANI. No single professional person I ran into knew how or where to go on with the conversation from there. It was like the concept of a professional having friends who were autistic was a foreign concept. I can't think of anything else that would account for the awkward silence that emerged time after time. What's even weirder is that at least some of these folks had heard me talk about myself as someone whose neurological wiring is different than most folks'. Seeing me actually wear that hat appeared to be disconcerting to professionals, unlike the HFAs I met who thought the fact that I wore more than one hat was neat. But then, I guess HFAs are a little less rigid in

their thinking than professional folks.

I'd like to comment on Jim's presentation before I close. It was packed. I glanced around me while he talked to observe reactions. There were many members of ANI that I recognized. The rest were presumably professionals and parents. In general, the audience members I was able to observe seemed caught up in his talk. I saw a lot of heads nodding "yes" during main points of Jim's talk that related to mistreatment in the name of love and denial of the right to be different.

I believe the audience reaction was overwhelmingly positive and that was, I think, confirmed by the number of parents who sought Jim out at later times to say how much they were moved by his talk. I also got the same feedback from folks I talked to after his talk.

This was a very exciting time. I found wonderful new relationships and even developed new familial connections. Many of us, maybe all, who are autistics or cousins spend much time and energy controlling our reactions, our movements, our speech, etc. We work hard to avoid standing out. As I spent time with cousins I felt a lot of my control mechanisms slipping away. I was among people who could accept and appreciate that my brain works a little differently. I could relax among friends. I think it was a process and awareness shared by others.

My thanks to Jim, Doyle, Toby, B.J., Kathy Lissner, Katherine French, Susan S., Wilham D., and Jean-Paul for making this a time of real magic.

[Editor's note: The sleep deprivation at the conference was mutual, due to *someone's* continual snoring and unwillingness to let a poor exhausted non-snorer sleep.]

A Letter To The Editor
(name withheld at author's request)

Dear Jim,

The newsletter was sure welcomed with open arms. Some of the subject matter helped me to think from a new perspective.

When I began to read the Editorial (Issue #1), my "hair went straight up in the air," my stomach started churning and something way down deep inside of me started screaming "danger....danger, stop reading, before it's too late," and I almost put the paper down.

I grew up feeling like there must be some deep dark secret buried on the inside of me. I was always very aware of being different, and it was not a positive difference. Like you, I lacked some level of social awareness. *To my thinking, everyone else was privy to some sort of social communication that I could not tap into.* They seemed to instinctively KNOW things that I could only guess at. I've yet to "break the code."

I too was abused by other children. I usually just "mentally" retreated and waited for it to end. When I was in late grade school I was introduced to the concept that "everybody is created for a purpose." It didn't take long for me to "recognize" my obvious purpose. I concluded that I was born to be a scapegoat, so that people who had important assignments could get rid of their pent-up frustration, and get on with their assignments. I never questioned this conclusion, because it gave me a purpose.

When you said that well-meaning people inadvertently teach autistic children that the only way they will be liked is to act like somebody else, I wanted to scream, Boy, how true that

is. I've spent my entire life pretending to be something I'm not. I once went to a "head shrink" because I was thinking on one level and functioning on another. After a number of "visits," he told me that I was very mentally gifted (high I.Q.) but I had spent most of my mental energy trying to appear normal. All he knew about my "unknown handicap" was that exhibiting social dyslexic and aphasic tendencies had prevented me from absorbing information from outside sources (parents, school, etc., etc.) so I had "failed" at nearly everything I tried to accomplish. And when I did succeed I was unable to acknowledge the accomplishment. By the time I finished college, I had required so much assistance that I saw no reason for participating in the graduation ceremony. I didn't think I deserved a diploma; after all I had "cheated" by accepting help. (I hid the diploma.)

At the end of the editorial, you repeated a question that I have been asking for as long as I can recall: How can I find or create a place in society (or a job) that uses my strengths and minimizes the effects of my weaknesses? There must be hundreds of high-functioning Autistics out there that need an Autistically-competent counselor. We have tried regular ones usually with self-defeating results. I would love to like being me. One function of ANI could be to identify such counselors (if they exist) and help those who need them make contact with them.

Sign me
"Still hoping"

[Editor's note: "Still hoping" also requested that autistic readers help develop a questionnaire to formulate questions about possible common experiences and characteristics that are not found in standard definitions of autism. This sounds like a fascinating and very important project. If you're interested in contributing to it, write down anything you can think of about yourself that is "different," even if it's not on the usual list of autistic symptoms, and send it to "Our Voice." These self-reports will be tabulated and may be quoted in a future issue, but all quotes used will be anonymous unless contributors give permission for their names to be used.]

I think the next letter is an excellent example of the kind of sharing of experience "Still hoping" is looking for. Some time ago James wrote to me and said he had read my essay in the book *High-Functioning Individuals With Autism*, and he wondered what I meant by the reference to being "invisible." James said that he had an experience he thought of as being invisible, but he didn't think it was likely that two people would independently come up with the same word to describe the same experience. I wrote back and tried to describe the experience I was referring to. James sent back the following much better description of the same experience.)

INVISIBILITY by James Sternberg

Thank you for your explanation of invisibility. It seems that we have indeed coined the same word to mean the same thing (or at least nearly the same thing). Let me see if I can explain this. When I am "invisible" I am aware of what is going on around me. Most of my abilities are still working. For example, I can walk around, and even drive a car. Somehow, as you said, I am unable to interact with those people around me. As a result, I am not noticed by people who are around me. Well, actually that is not true. People do notice me enough to walk around me instead of through me, but it seems to be more of an awareness of me as an object (like furniture) than as a person. When I am invisible, I find it extremely difficult to speak to people, and my interactions are usually limited to nodding "yes" or "no", and a few sparsely separated words. (This is not the best time to try to have a conversation with me.)

I have had nearly the same experience with waiting for a professor

as you have described, but my best example of being "invisible" happened recently. I was at the mall as part of my routine of going to the local book stores. I had decided that I wanted a cup of coffee, so I went to the coffee shop in the mall. I was "invisible" at the time. I waited in line to order coffee, and when I got to the front of the line, the people behind me started to walk in front of me. Furthermore, the woman behind the counter took these people's orders without taking any notice of me standing there. I was finding it very hard to speak (being invisible), my solution was to walk back to the end of the line and start over again.

I have never been able to adequately describe this to anyone. Even when I explain this as as precisely as I can, I have never been able to get the concept across. Perhaps the concept is too foreign to most people to understand, just as find other people's experiences very difficult to understand. I hope this is enough information (or not too much

NUDDS FOR ALEX!

by Dan Mori

Something wonderful happened in our family a little while back that just goes to show that some of the strengths that autistics have can help compensate for the weaknesses and help gain them some social acceptance.

My son Alex is a six-year-old high-functioning autistic who is mainstreamed in a first grade class. Alex's pragmatic speech skills are at the three year old level. He also has lots of problems interacting with other kids in the class that makes him seem at times quite aloof, detached, whiny and intransigent. While he has many fine qualities one might expect that he would be the target of a lot of first grade taunts and ostracism. This is not the case. In part, I believe, because he doesn't have a mean bone in his body. But also in part to his prodigious math and reading talents which have earned him a fair amount of respect.

Not too long ago something happened at school I'd like to share with you. It shows a number of things. First, that autistic kids can be made to feel (and be) part of a class if their special strengths are valued. And second, that even if it seems that they are completely disinterested with the children around them that sometimes down deep they desire to be part of things and are happy when that happens. It just needs to be facilitated with them in mind.

Alex's school's fifth grade had a contest to see who could come up with the most ways to pay \$1 using only change. A calendar would be awarded to the class in each grade that came up with the most ways. Well, Alex's

class got very excited because they thought that since they had Alex they couldn't lose.

Alex was very excited by this contest and came up with all 293 ways to combine coins to make a dollar. Needless, to say his first grade class won a calendar. When it was announced his class cheered, applauded him, and came over and hugged him. He was the only one in the school to get all 293 ways. Second place was 292. Third place was 135. Luckily, his mom was in school that morning to see all this. Alex was grinning from ear to ear. He got so excited he was rolling on the floor. His class was very proud that he was their class member. Everyone was patting him on the back. The fifth grade class that ran the contest came to see him and all congratulated him and decided that since he was the only one in the whole school to get all 293 ways that he would be awarded his very own calendar (that he is immensely proud of). His class had already decided to give him the class version. This was very sweet but I felt it should stay in the class since (surprisingly to us) Alex was happy that he won it for his class.

Anyway, this whole thing has made him very proud and happy and has clearly made him a full member of the class. His teacher says that the respect he gets for his talents makes children think there is something special about Alex and that makes them more patient with the things he has difficulty with.

Anyway, it was quite big news for us!

[Donna Williams writes that she has been diagnosed with Scotopic Sensitivity Syndrome, and has found tinted lenses to be helpful. For a vivid and detailed description of the benefits of the lenses, see Donna's article "The Day We Got Our Glasses" in the last 1993 issue of "The Maap." Following are some suggestions from Donna for determining whether an autistic person may have Scotopic Sensitivity Syndrome if the person is unable to communicate these difficulties.]

**HOW TO FIND OUT IF A PERSON WITH AUTISM MAY
HAVE SCOTOPIC SENSITIVITY SYNDROME**
by Donna Williams

* A related family history of dyslexia, learning difficulties or hyperactivity.

Person with autism:

* Sits in the dark, lies under the bed, sits in the cupboard, etc. (to cut down on the ongoing stress of light and color).

* Looks predominantly at feet whilst walking up the street or in shops (to avoid visual bombardment).

* Does the following compulsively or continually:

- rubs or pushes eyes (to relieve strain, self-stimulate and avoid usual bombardment by seeing colors rather than what is around them, get rid of visual "white noise" and afterimages)

- blinks or switches lights on and off continuously (to break up and slow down visual input)

- squints (to cut down light and narrow surrounding "context")

- turns one eye inwards or defocuses and appears to look through things (to put things out of focus, cut down on bouncing light and shadow and take the sharp edges off of what is seen)

- views scenes through cracks or tubes rather than directly (to cut

down on surrounding "context")

- seems often to have noticeably more difficulty staying aware/concentrating or keeping control of behavior when under fluorescent lights

- seems to lose sense of the purpose or meaning of what is seen, either totally or intermittently

- echopraxia--the generally unintentional "parroting" of what is seen

- has extreme reactions to certain colors, reflection, shadow or shine

- appears to see the part and lose the whole

- sees things in greater detail

- has parallel problems to any of the above with what is heard.

If you suspect a person with autism may have the syndrome but the person does not have the social or communication skills to confirm this, there are techniques which may help:

Keep a diary noting changes under the following conditions and observe general patterns:

- * Person's general behavior/responsiveness/awareness

when under fluorescent lights.

* Person's general behavior/responsiveness/awareness when under blue/red/yellow lighting (WITHOUT THE PERSON KNOWING IT IS BEING OBSERVED observe the person in his or her room under each of these lighting conditions for one to two weeks).

* Person's response when presented with blue/red/yellow colored cellophane. (Present one color each day and only one color at a time. Make allowances for the person having "a bad day" for other reasons. At the end of the person having experienced the different present the person with all of them and leave the person alone with the colors and observe WITHOUT THE PERSON KNOWING HE OR SHE IS BEING OBSERVED and note any preferences and aversions.)

* If the preferred color lighting and the preferred color cellophane are the same you can consider the person to have chosen (as best as he or she is able) a base color.

* Now go through the same procedure using purple/green/orange.

* When and if you get preferred responses to one of these colors alternate in use between the original base color and the preferred secondary color. This will help narrow down the range of colors which may help the person with autism.

After this it is relatively easy and inexpensive to construct a large box, crate or cubby house with cellophane walls and/or windows where the person with autism may choose to go. BE SURE NOT TO MAKE A FUSS ABOUT THIS OR DEMONSTRATE EXPECTATIONS THAT IT WILL HELP. LEAVE IT TO THE PERSON WITH AUTISM TO CHOOSE.

The next step is to approach a charity shop for some large, plastic secondhand glasses frames. Remove the lenses from them and replace them with cellophane lenses of the color preferred by the person with autism. In the event that the person has Scotopic Sensitivity and will benefit from tinted lenses it will do several things:

1. Help the person get used to glasses, frames and lenses.
2. Communicate to the person via your actions (rather than words) that you understand the sensory/perceptual difficulties and instill trust that you are not so non-understanding of his or her reality as you may have unintentionally appeared.
3. Be another step in confirming whether tinted lenses will help.

If the person with autism seems to cope and benefit from all of these stages, the next stage is to get a pair of large frames (to cut out as much unfiltered light as possible) fitted with colored lenses of the preferred color. The lenses ought to be a fairly strong shade of the chosen color at first and over time it will become apparent if the person with autism finds the lenses to be too dark in which case a lighter shade could be tried. If the person with autism is likely to destroy the frames, second-hand plastic frames would be best, most inexpensive, harder to break and less likely to cause injury. An optician should have a supply of ready-tinted plastic lenses in a variety of colors and shades and be able to fit the lenses into the frames quite cheaply and quickly. It would be best to phone around and find who stocks the color and shade of lenses you are looking for.

RESOURCES

SOURCES OF ADDITIONAL INFORMATION ABOUT SCOTOPIC SENSITIVITY SYNDROME:

Mrs. Ann Wright
The Irlen Centre East for
Perceptual and Learning Development
4 Park Farm Business Centre
Fornham St Genevieve
Bury St Edmunds
Suffolk, UK
IP28 6PX

Helen L. Irlen, M.A., M.F.C.C.
Irlen Institute for Perceptual
and Learning Development
5380 Village Road
Long Beach, California 90808
USA

NEW SUPPORT GROUP

There is a new support group. We have been told that it is the first one of its type anywhere. We are known as *A.G.U.A.*, Adult Gathering of United Autistics. We are a support group for adults—over 21—aimed at 30+ who are either:

mentally gifted, possessing a high I.Q. (it does not always show until facilitated communication is used)

true *savants*, with at least above average I.Q., etc., etc.

We will be involved in the first medical research on high-functioning adult autistics.

We do have a few members who may have an average intelligence. But we are really formulated for "high functioning" adults who happen to be autistic. We meet in southern California, mainly between Long Beach and L.A. and Orange County. We have some members who are "members by mail" because they live in other countries. If some of the "Our Voice" readers would like more information, they can write to either:

Jerry Newport	or	A.G.U.A.
135 Montana Ave.		c/o G.W.
#3		819 S. Bruce
St.		
Santa Monica, CA 90403		Anaheim, CA
92804		

DON'T MOURN FOR US
by Jim Sinclair

[This is an outline of the presentation I gave at the 1993 International Conference on Autism in Toronto. It is addressed primarily to parents.]

Parents often report that learning their child is autistic was the most traumatic thing that ever happened to them. Non-autistic people see autism as a great tragedy, and parents experience continuing disappointment and grief at all stages of the child's and family's life cycle.

But this grief does not stem from the child's autism in itself. It is grief over the loss of the normal child the parents had hoped and expected to have. Parents' attitudes and expectations, and the discrepancies between what parents expect of children at a particular age and their own child's actual development, cause more stress and anguish than the practical complexities of life with an autistic person.

Some amount of grief is natural as parents adjust to the fact that an event and a relationship they've been looking forward to isn't going to materialize. But this grief over a fantasized normal child needs to be separated from the parents' perceptions of the child they *do* have: the autistic child who needs the support of adult caretakers and who can form very meaningful relationships with those caretakers if given the opportunity. Continuing focus on the child's autism as a source of grief is damaging for both the parents and the child, and precludes the development of an accepting and authentic relationship between them. For their own sake and for the sake of their children, I urge parents to make radical changes in their perceptions of what autism means.

I invite you to look at our autism, and look at your grief, from our perspective:

Autism is not an appendage

Autism isn't something a person *has*, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is *pervasive*: it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person—and if it were possible, the person you'd have left would not be the same person you started with.

This is important, so take a moment to consider it: Autism is a way of being. It is not possible to separate the person from the autism.

Therefore, when parents say, "I wish my child did not have autism,"

what they're really saying is,

"I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead."

Read that again. This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces.

Autism is not an impenetrable wall

You try to relate to your autistic child, and the child doesn't respond. He doesn't see you; you can't reach her; there's no getting through. That's the hardest thing to deal with. Isn't it? The only thing is, it isn't.

true.

Look at it again: You try to relate as parent to child, using your own understanding of normal children, your own feelings about parenthood, your own experiences and intuitions about relationships. And the child doesn't respond in any way you can recognize as being part of that system.

That does not mean the child is incapable of relating *at all*. It only means you're assuming a shared system, a shared understanding of signals and meanings, that the child in fact does not share. It's as if you tried to have an intimate conversation with someone who has no comprehension of your language. Of course the person won't understand what you're talking about, won't respond in the way you expect, and may well find the whole interaction confusing and unpleasant.

It takes more work to communicate with someone whose native language isn't the same as yours. And autism goes deeper than language and culture; autistic people are "foreigners" in any society. You're going to have to give up your assumptions about shared meanings. You're going to have to learn to back up to levels more basic than you've probably thought about before, to translate, and to check to make sure your translations are understood. You're going to have to give up the certainty that comes of being on your own familiar territory, of knowing you're in charge, and let your child teach you a little of her language, guide you a little way into his world.

And the outcome, if you succeed, still will not be a normal parent-child relationship. Your autistic child may learn to talk, may attend regular classes in school, may go to college, drive a car, live independently, have a career—but will never relate to you as other children relate to their parents. Or your autistic child may never speak, may graduate from a self-contained special education classroom to a sheltered activity program or a residential facility, may need lifelong full-time care and supervision—but is

not completely beyond your reach.

The ways we relate are *different*.

Push for the things your expectations tell you are normal, and you'll find frustration, disappointment, resentment, maybe even rage and hatred.

Approach respectfully, without preconceptions, and with openness to learning new things, and you'll find a world you could never have imagined.

Yes, that takes more work than relating to a non-autistic person. But it can be done—unless non-autistic people are far more limited than we are in their capacity to relate. We spend our entire lives doing it. Each of us who does learn to talk to you, each of us who manages to function at all in your society, each of us who manages to reach out and make a connection with you, is operating in alien territory, making contact with alien beings. We spend our entire lives doing this. And then you tell us that we can't relate.

Autism is not death

Granted, autism isn't what most parents expect or look forward to when they anticipate the arrival of a child. What they expect is a child who will be like them, who will share their world and relate to them without requiring intensive on-the-job training in alien contact. Even if their child has some disability other than autism, parents expect to be able to relate to that child on the terms that seem normal to them; and in most cases, even allowing for the limitations of various disabilities, it is possible to form the kind of bond the parents had been looking forward to.

But not when the child is autistic. Much of the grieving parents do is over the non-occurrence of the expected relationship with an expected normal child. This grief is very real, and it needs to be expected and worked through so people can get on with their lives—

but it has *nothing* to do with autism.

What it comes down to is that you expected something that was

tremendously important to you, and you looked forward to it with great joy and excitement, and maybe for a while you thought you actually had it—and then, perhaps gradually, perhaps abruptly, you had to recognize that the thing you looked forward to hasn't happened. It isn't going to happen. No matter how many other, normal children you have, nothing will change the fact that *this* time, the child you waited and hoped and planned and dreamed for didn't arrive.

This is the same thing that parents experience when a child is stillborn, or when they have their baby to hold for a short time, only to have it die in infancy. It isn't about autism, it's about shattered expectations. I suggest that the best place to address these issues is not in organizations devoted to autism, but in parental bereavement counseling and support groups. In those settings parents learn to come to terms with their loss—not to forget about it, but to let it be in the past, where the grief doesn't hit them in the face every waking moment of their lives. They learn to accept that their child *is* gone, forever, and won't be coming back. Most importantly, they learn *not to take out their grief for the lost child on their surviving children*. This is of critical importance when one of those surviving children arrived at the same time the child being mourned for died.

You didn't lose a child to autism. You lost a child because the child you waited for never came into existence. That isn't the fault of the autistic child who *does* exist, and it shouldn't be our burden. We need and deserve families who can see us and value us for ourselves, not families whose vision of us is obscured by the ghosts of children who never lived. Grieve if you must, for your own lost dreams. But don't mourn for us. We are alive. We are real. And we're here waiting for you.

This is what I think autism societies should be about: not mourning for what never was, but exploration of what is. We need you. We need your help and your understanding. Your world is not very open to us, and we won't make it without your strong support. Yes, there is tragedy that comes with autism: not because of what we are, but because of the things that happen to us. Be sad about that, if you want to be sad about something. Better than being sad about it, though, get mad about it—and then *do* something about it. The tragedy is not that we're here, but that your world has no place for us to be. How can it be otherwise, as long as our own parents are still grieving over having brought us into the world?

Take a look at your autistic child sometime, and take a moment to tell yourself who that child is not. Think to yourself: "This is not my child that I expected and planned for. This is not the child I waited for through all those months of pregnancy and all those hours of labor. This is not the child I made all those plans to share all those experiences with. That child never came. This is not that child." Then go do whatever grieving you have to do—away from the autistic child—and start learning to let go.

After you've started that letting go, come back and look at your autistic child again, and say to yourself: "This is not my child that I expected and planned for. This is an alien child who landed in my life by accident. I don't know who this child is or what it will become. But I know it's a child, stranded in an alien world, without parents of its own kind to care for it. It needs someone to care for it, to teach it, to interpret and to advocate for it. And because this alien child happened to drop into my life, that job is mine if I want it."

If that prospect excites you, then come join us, in strength and determination, in hope and in joy. The adventure of a lifetime is ahead of you.

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